



DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES

370 L'Enfant Promenade, S.W.  
Washington, D.C. 20447

DEC 13 2011

Roger Bearden, Chair  
NYS Commission on Quality of Care & Advocacy for Persons with Disabilities  
401 State Street  
Schenectady, NY 12305-2397

Dear Mr. Bearden,

The Administration on Developmental Disabilities (ADD) would like to thank you and your staff for all your time and effort related to the site visit of the New York Commission on Quality of Care & Advocacy for Persons with Disabilities (CQC). We appreciated having the opportunity to visit your program and learn more about the work of the CQC.

ADD conducted a Monitoring, Technical Assistance, Review System (MTARS) site visit of the New York Protection and Advocacy agency (P&A) on July 13-15, 2011. ADD's visit was prompted by events described in recent New York Times articles, which heightened ADD's concerns about the P&A.

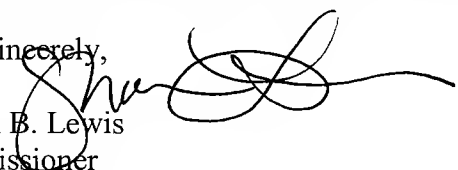
The purpose of the MTARS site visit was to review your program from a monitoring and a technical assistance perspective. The site visit focused on ensuring the New York P&A is meeting the P&A program requirements and on assisting you in advancing your work to improve the lives of people with developmental disabilities and their families. Most specifically, ADD was interested in knowing the extent to which the Agency has the authority and independence to carry the functions of the P&A.

After careful review of the program, ADD has determined that the CQC is out of compliance with several requirements in the DD Act. The compliance issues are listed in the enclosed Attachment A. Additional concerns are outlined in the enclosed Attachment B.

We request that the New York CQC respond with a corrective action plan within 30 days, or by **Friday, January 13, 2011** to ensure that the P&A are taking the proper steps to comply with the program requirements. Please direct your plan and any questions you may have to your ADD Project Officer, Brianne Burger, at [brianne.burger@acf.hhs.gov](mailto:brianne.burger@acf.hhs.gov).

We look forward to working with you on enhancing the New York CQC's ability to serve people with developmental disabilities and their families.

Most sincerely,

  
Sharon B. Lewis  
Commissioner

Administration on Developmental Disabilities

## ATTACHMENT A - PROGRAM FINDINGS

After careful review of the program, ADD has determined that the CQC is out of compliance with several requirements of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), raising significant questions about the authority and independence of this P&A. The major deficiencies we identified on our visit are listed in this chart. The CQC must provide ADD within 30 days of receipt of this letter a corrective action plan that addresses the program issues. The CQC must also provide monthly program reports to ADD demonstrating progress in addressing the program issues cited in the chart below.

CITATION	SELECT FINDING
<p>42 USC 15043  <i>(a) SYSTEM REQUIRED.</i>  <i>In order for a State to receive an allotment under subtitle B or this subtitle-</i>  <i>(1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;</i>  <i>(2) such system shall-</i>  <i>(G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;</i></p>	<p>A lack of independence from agencies that provide treatment and services to individuals with developmental disabilities. The gubernatorial appointment of the Chair and Commissioners and the influence of the political structure (due to staff reporting lines) call into question the independence of the agency. The reporting structure does not support the NY P&amp;A's independence and objectivity in administering the program; the CQC Director reports through the same structure that is also responsible for directing agencies providing treatment and services to individuals with developmental disabilities, including the Director of the Office of People with Developmental Disabilities, and the P&amp;A is expected to share sensitive investigative information with the Governor's leadership team.</p>
<p>42 USC 15043  <i>(a) SYSTEM REQUIRED.</i>  <i>In order for a State to receive an allotment under subtitle B or this subtitle-</i>  <i>(1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;</i></p>	<p>CQC implements the P&amp;A requirements through subcontracting entities. CQC must demonstrate adequate monitoring and oversight of subcontracting entities to ensure compliance with all requirements of the DD Act.</p>
<p>42 USC 15042  <i>(5) MONITORING THE ADMINISTRATION OF THE SYSTEM. -In a State in which the system is housed in a State agency, the State may use not more than 5 percent of any allotment under this subsection for the costs of monitoring the administration of the system required under section 143(a).</i></p>	<p>Budget documents demonstrating federal program administration expenses versus program implementation expenses (not to exceed 5%), and clearly delineating various federal funding streams from one another and from state funding, have not been made available to ADD staff.</p>

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<p>45 CFR 92.20  <i>(a) A State must expend and account for grant funds in accordance with State laws and procedures for expending and accounting for its own funds. Fiscal control and accounting procedures of the State, as well as its subgrantees and cost-type contractors, must be sufficient to—</i>  <i>(2) Permit the tracing of funds to a level of expenditures adequate to establish that such funds have not been used in violation of the restrictions and prohibitions of applicable statutes.</i></p> <p>AND</p> <p>45 CFR 92.20  <i>(b) The financial management systems of other grantees and subgrantees must meet the following standards:</i>  <i>(2) Accounting records. Grantees and subgrantees must maintain records which adequately identify the source and application of funds provided for financially-assisted activities. These records must contain information pertaining to grant or subgrant awards and authorizations, obligations, unobligated balances, assets, liabilities, outlays or expenditures, and income.</i></p>	<p>Budget documents demonstrating that federal P&amp;A funds (including funds to contractors) have been expended consistent with federal requirements have not been made available to ADD staff.</p>
<p>42 USC 15043  <i>(a) SYSTEM REQUIRED.</i>  <i>(2) such system shall-</i>  <i>(M) provide assurances to the Secretary that</i></p>	<p>Unclear budget management and delineation between federal and state funds. State appropriations and state mandates may cause federal funds to supplant state resources.</p>

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<p><i>funds allotted to the State under section 142 will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the allotted funds are provided;</i></p>	
<p>42 USC 15043  <i>(a) SYSTEM REQUIRED.  (2) such system shall-  (k) hire and maintain sufficient numbers and types of staff (qualified by training and experience) to carry out such system's functions, except that the State involved shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the system, to the extent that such policies would impact the staff or functions of the system funded with Federal funds or would prevent the system from carrying out the functions of the system under this subtitle;</i></p>	<p>The current organizational structure prevents the CQC Director from having the ability to apply independent discretion in hiring decisions, reductions in force or exemptions from prohibitions on staff travel.</p>
<p>45 CFR 1386.22  <i>(e) The client's record is the property of the Protection and Advocacy System which must protect it from loss, damage, tampering, or use by unauthorized individuals. The Protection and Advocacy System must: (1) Keep confidential all information contained in a client's records, which includes, but is not limited to, information contained in an automated data bank. This regulation does not limit access by parents or legal guardians of minors unless prohibited by State or Federal law, court order or the rules of attorney-client privilege; (2) Have written policies governing access to, storage of, duplication of, and release of information from</i></p>	<p>The contractors responsible for implementing NY P&amp;A programmatic activities have inconsistent protocols on client confidentiality and records management. CQC has not established explicit and consistent policies for their contracted services regarding records management and information sharing.</p> <p>The confidentiality of P&amp;A data and records must be ensured. It is unclear whether adequate protections are in place to ensure that state data and records that are publicly available under state requirements are not inappropriately comingled with federal P&amp;A information.</p>

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<p><i>the client's record; and (3) Be authorized to keep confidential the names and identity of individuals who report incidents of abuse and neglect and individuals who furnish information that forms the basis for a determination that probable cause exists.</i></p>	
<p>42 USC 15043  (a) <b>SYSTEM REQUIRED.</b>  (2) <i>such system shall-</i>  (C) <i>on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system's activities;</i>  (D) <i>on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on-</i>  (i) <i>the goals and priorities established by the system and the rationale for the establishment of such goals; and</i>  (ii) <i>the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.), and the Protection and Advocacy for Mentally Ill Individuals Act of</i></p>	<p>No evidence of data driven strategic planning to establish goals. NY's PADD priorities do not necessarily reflect the DD Act areas of emphasis. Instead they broadly include specific case types (i.e. benefits eligibility), and allow contractors wide discretion to focus on individual client work that may not be consistent with stated annual goals, state needs, public priorities and/or the purpose of the DD Act (i.e. support for segregated educational placements and segregated residential school programs, little emphasis on abuse and neglect cases).</p> <p>Priority setting is not done through an established process allowing for substantive and meaningful public input. Current priorities are determined through a pre-set checklist distributed by the P&amp;A, the checklist has not substantively changed in several years.</p> <p>The priority setting process does not adequately support public input. Public outreach is minimal, no demonstrated outreach to underserved populations, and most outreach efforts are dependent upon individual contractors' efforts and therefore inconsistent across the state. The opportunity to provide comments is not well known by stakeholders across the state.</p> <p>Intake protocol at CQC is not reflective of P&amp;A values and mission; contractors have their own intake protocol; intake and referral to contractors is largely undefined and based on individual staff judgments.</p>

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<p><i>1986 (42 U.S.C. 10801 et seq.), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), and activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012);</i></p>	
<p>45 CFR 1386.21  <i>(g) Each P&amp;A system that is a public system without a multimember governing or advisory board must establish an advisory council in order to provide a voice for individuals with developmental disabilities. The Advisory Council shall advise the P&amp;A on program policies and priorities and shall be comprised of a majority of individuals with developmental disabilities who are eligible for services, or have received or are receiving services or parents or family members, (including those representing individuals with developmental disabilities who live in institutions and home and community based settings), guardians, advocates, or authorized representatives of such individuals.</i></p>	<p>Under the current Advisory Council composition, there is not a majority of individuals with developmental disabilities and family members.</p> <p>Based on ADD interviews with the Chair of the Advisory Council and one other member, the Advisory Council has little to no input on adding or revising priorities, goals, or program policies.</p>

## ATTACHMENT B – ADDITIONAL FINDINGS

The additional concerns identified during the ADD visit regarding the P&A programmatic activities are listed here:

1. CQC staff appear to be focused primarily on state law mandates, sometimes to the exclusion of the P&A programmatic responsibilities which are managed almost exclusively by contractors
2. CQC's currently established goals do not include the ability to act on the abuse and neglect issues within the DD system highlighted in the NY Times and recent scrutiny of basic health and safety issues of people with developmental disabilities across the state
3. CQC and its contractors do not adequately demonstrate evidence across the state of unaccompanied access at reasonable times to any individual with a developmental disability in a location in which services, supports or other assistance are provided.
4. Data and information across parts of the P&A system are not integrated in a manner that allows for aggregate analysis while retaining confidentiality. Contractors maintain their own records and CQC employees maintain other client records without consistent and defined protocol.
5. Many cases have been resolved, but remain open in the system – there is a need to update and archive database, ensure data collection is accurate and current.
6. There is a need to improve outreach and marketing of the P&A services to the public.
7. Lack of internal policies: transition planning/written protocol for exiting staff, written protocol for records maintenance, clear budget management documentation.
8. Grievance procedure unclear and complicated, making it difficult for clients to navigate.
9. Underserved populations not represented on staff; lack of employed individuals with disabilities.
10. CQC has very minimal engagement with the NY DD Council and NY UCEDDs. There is a lack of statewide collaboration – each contractor's relationship with the DD Network varies, and there is little evidence of coordination of services with the entities carrying out related activities consistent with 42 U.S.C. § 15043(a)(2)(D)(ii).
11. The Advisory Council does not have a policy manual, protocols, term limits, trainings, or orientations. No conflict of interest policy has been implemented. The Advisory Council has limited contact with CQC and no contact with contractors, yet members expressed strong interest in a higher level of involvement.
12. Information and Referral written materials need to be accessible in formats and languages other than English. Website is not 508 compliant or accessible to people with disabilities. It is unclear whether physical offices for all CQC staff and contractors are accessible to people with disabilities.

The team notes that the upcoming completion of current 5 year contracts creates an opportunity to implement improvements and potentially revisions to the current approach, including:

- stronger controls, oversight and monitoring of contracts and activities;
- more uniform strategic planning and goal setting;
- stronger identity for CQC entities as a single statewide protection and advocacy system;
- consistency in billing, reporting, data collection and communication.